

**Autism Partnership Meeting**

11/01/22 at 10:30-12:30pm

**Attendees:**

Valerie Fitch	Chair / Person on the Autistic Spectrum
Laura Ferguson	Herefordshire Council
John Gorman	Herefordshire Council
Paul Choppen	Herefordshire Council
Neil White	CCG
Rachael Skinner	Lead for LeDeR
Mary Simpson	Healthwatch
Debbie Hobbs	Herefordshire and Worcestershire NAS / Parent Carer Voice
James Baker	Hereford Make
Rebecca Ashton	Person on the Autistic Spectrum
Helen George	Herefordshire Council
Alexia Health	Herefordshire Council
Julie Walker	Herefordshire Council
Rob Gorle	ACSYLE
Gill Gorle	ACSYLE

**Apologies:**

Jenny Dalloway	Herefordshire and Worcestershire CCG
Richard Keble	Public Health
Brigid McGrath	Brightfire Holistic

**Introductions and Apologies**

Valerie welcomed everyone to the meeting and Paul went through the Apologies.

**Minutes from Previous Meeting and Matters Arising**

John went through the Actions from the previous meeting.

**Talk Community Representation** - Emily Lowe the Talk Community Lead will try and attend APB meeting in the future.

**KPI spreadsheet** - Valerie has added the number of enquires to the Hereford NAS branch to the KPI spreadsheet. See agenda item below for further updates.

**Autism Terminology** - A meeting hasn't been set up to discuss this yet with the Taskforce group.

**Action 1** - Valerie to make sure a meeting with the Taskforce group regarding Autism Terminology is set up soon.

**Matters Arising. Updates**

**Disclosure of Interests** - John ask for Discloser of Interests to be added as an item of future meetings. Members moving forward will need to disclose any conflicts of interest they may have on items being discussed at the meetings. Any members who have a conflict of interest to an item to be discussed will be asked to leave the meeting while said item is being discussed.

**Action 2** - Paul will add Disclosure of Interests as a regular item for future meetings. He will also draft the wording to be added to the invites/agendas of these meetings.

### **ICS updates - Valerie Fitch**

**Expression of Interests Group (working title)** - Valerie Fitch and Rebecca Ashton along with two members of Worcestershire's APB are part of a group to make GP Practices more autism friendly.

Valerie and Rebecca are visiting the five PCN's in Herefordshire in February to make sure their surgeries are autism friendly.

**Training Videos for GPs** - A Media Company has been given a grant of £10,000 to produce a snapshot video of a patient's journey through the GP surgery. The video will include autistic actors from across Herefordshire and Worcestershire. Valerie will share the video with the Board once it is complete.

**Autism Champion** - Bernadette Louise has been chosen as the Autism Champion for Herefordshire and Worcestershire. The role is initially for 6 months but could be extended to 3 years. Bernadette currently chairs Worcestershire's APB.

**Action 3** - Members agreed with Valerie's recommendation to invite the Autism Champion to our next Autism Partnership Board meeting.

**Dashboard** - Laura suggested having the ICS's 3 Year Plan Dashboard of all the projects currently ongoing to be a standing item at future Board meetings.

Concerns were raised on it being over complex in its current form to be understood by APB members.

**KPI Spreadsheet (Key Performance Indicators for the New Diagnostic Service)** – Valerie was disappointed the spreadsheet failed to make the agenda for the last ICS Programme Assurance Board meeting. However Valerie and Laura had an in-depth discussion on the spreadsheet with Jenny Dalloway on its importance in evaluating and assessing the performance of the future provider of the diagnostic pathway and its inclusion in the contract with the new provider. The start date of the new provider has been pushed back from the 1<sup>st</sup> of April to the 1<sup>st</sup> of July.

**Action 4** - Jenny will get information to the Board by the middle of February on the CCG's current performance indicators and evaluation data from the current provider Family Psychologists.

James also asked if during the tendering process if the diagnostic pathway is a public service and whether there had been any consideration of the social impact or social responsibility of the service.

Laura said the question should be taken back to the CCG.

### **12 month Pilot Project 14-18 Post Diagnostic Support Services – Neil White CCG**

The service will be part of the assessment process for young people from 14-18<sup>th</sup> birthday who have had an escalation in their mental health to tier 4 CAMS. The pilot will be for 12 months starting from April with a full evaluation of the effectiveness of the service afterwards.

Three providers have sent Neil their proposal ranging from two charities one offering peer support, another offering 2 support workers and a company proposing an app (Brain in Hand), including 24 hour mental health support.

Neil will be holding a workshop event on the 25<sup>th</sup> of January discussing the proposals. This will include a presentation from an autistic representative from Brain in Hand demonstrating their app.

**Action 5** - Neil will send the presentations on the proposals and links to a Mentimeter poll to Paul who will share with the board.

### **Police reports – Valerie Fitch**

Valerie reported that she had not been informed of any further autistic hate crimes recurring in Herefordshire since the last meeting.

Valerie also updated the board on the incident discussed at the last meeting concerning an autistic individual who had been beaten up and the police had failed to follow due process. The perpetrator has since died due a drugs overdose and hence there will be no restorative justice.

The victim advised the Board of the learning that should come out of the incident including:

- The Police failed to give the victim a Victim Support card.
- The Police failed to ask the victim for a statement.
- The Police officer dealing with the incident failed to understand the victim was autistic even though the individual had stated it.
- The police also closed the case without asking the victim for their preferred outcome.
- The police also failed to supply an autistic specialist for the victim to speak to.

Valerie mentioned that she will be doing more training sessions with the police so they are better educated on how to respond in the future.

Debbie informed the group that there had been two hate crimes involving young people in Bromyard over the Christmas period. The police currently haven't been in touch with the parents. Debbie will liaise with Valerie about the incidents.

### **NAS updates – Debbie Hobbs**

The NAS has been overwhelmed with recently diagnosed under 5 children. Debbie has been signposting them on to Early Help and the Portage Workers. Debbie hopes to put in a bid in for the Autism Support grants to explain what Autism is to the parents and young autistic children getting diagnosed.

The NAS is also due to start work with Wye Valley NHS backroom staff on understanding autism due to high levels of bullying towards autistic staff within the past couple of months.

The branch has been chosen to be a pivotal person on Songs of Praise which will be recorded at Hereford Cathedral for Autism Acceptance Week (formally World Autism Awareness Week). Autism Acceptance Week will run from the 28<sup>th</sup> March to the 3<sup>rd</sup> April.

Please send any information on events being held for Autism Acceptance Week to Paul who will share with Board members.

## **LeDeR-(programme to improve services by learning from the premature deaths of people with a learning disability and autism) - Rachael Skinner**

Rachael went through her presentation explaining the origins of the LeDeR programme and describing that the national policy for LeDeR was published last year with the intent to include autism in the LeDeR programme. Initially the focus will be on adults with a clinical record of being diagnosed.

Rachael raised concerns about it currently being more difficult to get notifications of the deaths of people with autism. She highlighted the importance of getting people with autism formally diagnosed and a clinical record of their diagnosis.

Rachael highlighted the need to get autistic representation on the LeDeR panels.

One of the key themes of the LeDeR Strategy and Delivery Plan will be raising awareness of being able to notify the death of a person on the autistic spectrum. The reviews will help identify how local services influence health outcomes along with what reasonable adjustments can be made to services.

See attached for more information.

**Action 6** - James said he would forward some information from Project Aspie about the reason behind premature deaths of people on the autistic spectrum to Paul to forward to Rachael.

## **Self Assessment - John Gorman**

John has reviewed the previous (2018) autism self-assessment which is reported nationally by all Local Authorities. He noted that during the pandemic this was not requested, and it would be timely to review Herefordshire's current position in readiness for the future strategy and also a future self-assessment return in advance. John advised he would review and update the assessment and bring to a future meeting to look at key areas for improvement in more detail.

**AOB**

## **GP Training – Mary Simpson**

The McGowan training has been pushed back till September due to them needing more experts by experiences to be involved in delivering the training.

## **Brightfire – Rebecca Ashton**

Are creating videos about autism for their website. Rebecca asked members to email suggestions on topics they think they should cover.

## **60<sup>th</sup> Anniversary of the National NAS – Debbie Hobbs**

Debbie also mentioned that this year was the 60<sup>th</sup> anniversary of the National NAS and that celebrations were expected to occur.

## **The Audiology, Learning Disability and Autism Project - being led by Dr Siobhan Brennan**

The project is to explore the barriers and challenges autistic adults and children face when accessing Audiology (hearing) services, such as to have a hearing test.

They are running online focus groups and interviews with autistic people, and with carers and parents/guardians.

See attached for more information.

### **Hereford Make - Neuro-Diversity Training - James Baker**

James discussed the DWP Autism training for the workplace. James said it was useful understanding what the government's standards were and understanding where the person delivering the training lacked guidance in what to cover. James felt the training had been simplified to Neuro-Diversity training rather than specific Autism training.

### **Peer Support - Julie Walker**

Julie brought up the point that through her apprenticeship she has done some work on Autism. One of the themes as part of her research was isolation and difficulties in mental health due to communication difficulties in connecting with others.

Julie highlighted the importance and benefits of peer support and questioned why there didn't seem to be any specialist peer support for autistic people in the county.

Rebecca highlighted that Brightfire was aiming to offer autistic peer support in the near future and will keep the Board updated.

Next Meeting and subject:

### **Decision - Valerie Fitch**

Valerie asked the Board whether they would be happy to have the Autism Partnership Board meetings every 2 months to coordinate with the Worcestershire APB and the meetings of both APB's chairs and leads. All agreed.

Subsequently the next meeting has been scheduled for the 29<sup>th</sup> March from 10:30am-12:30pm.

The Autism Champion will be invited to the next meeting and given time on the agenda. Any further suggestions for agenda items please send to [paul.choppen@herefordshire.gov.uk](mailto:paul.choppen@herefordshire.gov.uk)

### **Actions**

Valerie	<b>Action 1</b>	To make sure a meeting with the Taskforce group regarding Autism Terminology is set up soon.
Paul	<b>Action 2</b>	To add Disclosure of Interests as a regular agenda item for future meetings. He will also draft the wording to be added to the invites/agendas of these meetings.
Paul/Valerie	<b>Action 3</b>	To invite the Autism Champion to our next Autism Partnership Meeting.
Jenny Dalloway	<b>Action 4</b>	To send Valerie the CCG's current performance and evaluation data on the Family Psychologists current Diagnostic Pathway by the middle of February.
Neil White/ Paul Choppen	<b>Action 5</b>	Neil will send the presentations on the proposals and links to a Mentimeter poll to Paul who will share with the Board

Valerie	<b>Action 1</b>	To make sure a meeting with the Taskforce group regrading Autism Terminology is set up soon.
James Baker	<b>Action 6</b>	James to send Paul some information from Project Aspire to be forwarded to Rachael Skinner

**Attachments:**

- Learning from Lives and Deaths (LeDeR) report
- Aspies into everything - Aspergers charity information
- Improving hearing services for autistic people Easy Read version
- Improving hearing services for autistic people - no pictures - poster



Herefordshire and  
Worcestershire  
Clinical Commissioning Group

# Learning from lives and deaths (LeDeR) Programme update- including autistic people

Rachael Skinner- Deputy Chief Nurse

January 2022

# Learning from the lives and deaths of people with a learning disability and autistic people (LeDeR) update

## History of LeDeR

- Programme in place since 2017. Has to date focused on people with a learning disability.
- Programme aim is to improve services (and outcomes for people) by learning about what works and what things influence poorer health
- Person's death notified to LeDeR programme through a web based reporting system
- Retrospective review of how a person's health and wellbeing was managed
- Recommendations are made to reflect gaps that require improvement or areas of good practice that need to be more widespread

## Change in scope of LeDeR to include autistic people

- Change in scope introduced in national LeDeR policy published in March 2021
- From February 2022 the LeDeR reporting system will be able to accept a notification for an autistic person to trigger a LeDeR Review. The person who died must be 18 years of age or over and have a diagnosis of autism that is confirmed within a clinical record.



# Learning from the lives and deaths of people with a learning disability and autistic people (LeDeR) update

## Next steps

- LeDeR Reviewers undertake additional training to help raise awareness of health needs associated with the lives of autistic people
- Raise awareness amongst those who are most likely to make notifications
- Ensure autistic people are part of the decision making to agree Review recommendations (LeDeR Learning into Action Panel)

## How will LeDeR lead to improvement in health for autistic people?

- LeDeR Reviews make recommendations for service improvement
- Key recommendation themes will form part of the LeDeR Strategy 3 Year delivery plan (2022-2025)
- The Delivery plan in year one will aim to understand what influences the health of autistic people. The plan will be reviewed annually to incorporate new learning
- Existing LeDeR Priority workstreams will be reviewed to reflect the needs of autistic people
- Progress with meeting the LeDeR delivery plan will be reported to the Tackling Health Inequalities Board

## LeDeR Strategy- Key priority areas

1. **Annual Health Checks and Health Action Plan** completion, to inform robust reviews of a person's health needs and support meaningful plans to work toward sustaining or improving health outcomes.
2. Achieving the best life chances for those at risk of dying from **respiratory illness**.
3. Supporting people's **emotional and mental health needs**.
4. Supporting people to make decisions about their care and improving their experience if they have a **life limiting illness or are nearing their last months or days of life**.
5. Zero tolerance to **avoidable deaths related to bowel impaction or bowel disease**
6. Ensuring that those living with **obesity** and their carers have accessible support to make informed choices about lifestyle factors that can improve their health.
7. Ensure carers, care staff and clinicians are skilled in enabling everyone to be supported to be part of **decision making about their health** and where this is not possible that Mental Capacity Act standards are followed, and Best Interest decisions are made and communicated
8. Enabling our ICS **workforce** to be equipped to recognise the essential needs of people with a learning disability, autistic people and their carers, so that they can provide effective care that achieves positive outcomes.

In addition to themes arising from Reviews there are other priorities that are important for us to improve:

9. Ensuring that we are **sharing information about what we are learning** and how we are working together to make improvements. We want to do more to give recognition and thanks where areas of good practice are identified within Reviews and to share examples of good practice with others as another way of supporting improvement.
10. Ensuring that the **notifications that we receive are representative of our local communities**. We need to make sure that we are doing all that we can to learn from every opportunity available to us. This includes people from ethnic minority backgrounds, autistic people, people who live in very rural areas.
11. Meeting the standards of the national LeDeR Policy. This includes having a dedicated workforce to undertake reviews in a timely way and making sure that our systems of reporting and monitoring helps us know if we are doing what we set out to achieve. It also includes ensuring that we continue to enable experts by lived experience (people with a learning disability and their family or paid carers) to be a key part of the LeDeR Programme locally. **During 2021/2022 this will expand to include Autistic people.**

# How to tell LeDeR about the death of an adult diagnosed with autism

Anyone can notify LeDeR of a death

- A death can be notified by completing an online form within this link [Report the death of someone with a learning disability \(leder.nhs.uk\)](https://www.leder.nhs.uk/report-death-learning-disability)
- For help with completing the form a telephone helpline can be accessed **01278 727411** (Monday to Friday, 8.30am to 4.30pm - except public holidays)

ASPIE



Aspies Into Everything

Asperger's is part of the autistic spectrum and a hidden disability. 'Aspie' is an affectionate name for a person with Asperger's.

Asperger's is a neurological difference and a hidden disability. It is a high anxiety, lifelong condition. There is no cure. Adults with Asperger's think differently and learn differently. Their lack of social and communication skills frequently lead to them being misunderstood, isolated and disadvantaged, missing out in education and employment opportunities because they are different. Additional difficulties are the accompanying co-occurring conditions such as depression, dyspraxia, dyslexia, OCD etc and the sensory issues which impede their daily functioning and quality of life.

They are, however, highly intelligent and long for acceptance, inclusion and employment and can, with their special abilities, make a substantial contribution to society if they receive appropriate support.

**Founded in desperation by an Asperger adult, ASPIE was registered as a company limited by guarantee in June 2011 and achieved charity status in January 2012.**

Operating as a self-help and support group, ASPIE provides vital services and is a lifeline to adults who live with the complexities of Asperger's. The aims are to provide Asperger adults with an environment in which they are given the opportunity to:

- Understand themselves and gain confidence
- Improve communication and social skills
- Build a network of support in the skills required for independent living
- Access suitable education and training courses
- Development employment application skills

#### Research shows:

- One person in 45 thought to be on the autistic spectrum
- 79% of people on the autistic spectrum feel socially isolated
- **Many people with autism will not reach their 40th birthday**
- People with autism without a learning disability are 9 times more likely to die by suicide than the general public
- **Only 16% of people on the autistic spectrum are in fulltime paid employment**
- Graduates with a social/ASD condition are less likely to be in permanent employment
- **At all levels, graduates with a social/ASD condition are most likely to be carrying out voluntary work**

Professor Simon Baron-Cohen Director of Cambridge University's Autism Research Centre  
*"Adults with Asperger Syndrome often suffer secondary depression due to social isolation, loneliness, social exclusion, lack of community services, under-achievement and unemployment. Their depression and risk of suicide are preventable with the appropriate support. This study should be a wakeup call for the urgent need for high quality services to prevent the tragic waste of even a single life."* [www.cam.ac.uk/.../adults-with-asperger-syndrome-at-greater-risk-of-suicide](http://www.cam.ac.uk/.../adults-with-asperger-syndrome-at-greater-risk-of-suicide)

From our experience the most important need for adults with Asperger's is acceptance and friendship closely followed by employment and a desire to make a contribution to the community. ASPIE's long term aim is to provide a continuous stable base, a central point of comfort and friendship, with activities, counselling, mentoring and advocacy to open up opportunities, possibilities and the bringing about of positive change in reducing isolation, anxiety, depression, self-harm and suicidal tendencies to improve confidence and self-worth and to make life healthier, less stressful and happier for members while supporting their efforts in maintaining friendships, education and employment.

# Improving hearing services for autistic people

Are you an **autistic person**? Or are you a carer or parent/guardian of an autistic person?



Do you live in the **United Kingdom**?

Have you used **hearing (Audiology) services**? Or have you tried to use hearing services?



Can you tell us what it is like to use hearing services?

Do you have access to a computer, laptop, mobile, or tablet? Can you use **Zoom** on it?



If you said **yes**, we would like to invite you to a **focus group**. The group will take place **online**.

There will be up to 6 autistic people at the group.



The group will take 1 hour.



We will ask you what it is like to use hearing services and how hearing services could be better.

If you take part, you will be reimbursed for your time.

**Please contact us** if you are interested in taking part or if you have any questions:



[Shanice.Thomas@manchester.ac.uk](mailto:Shanice.Thomas@manchester.ac.uk)

[Siobhan.Brennan@manchester.ac.uk](mailto:Siobhan.Brennan@manchester.ac.uk)



<https://sites.manchester.ac.uk/aldap/>

*This project has been reviewed and approved by the University of Manchester Research Ethics Committee. Project no.: 2021-11714-19995*

## Improving hearing services for autistic people

Are you autistic? Or are you a carer or parent/guardian of an autistic person?

Can you tell us what you think about hearing services?

We would like to invite you to take part in a focus group.

Researchers at The University of Manchester are looking at the challenges that autistic adults and children face when they access hearing (Audiology) services, such as to have a hearing test. To take part, you need to:

- Have a diagnosis of autism. Or you will be a carer or parent/guardian of an autistic person.
- Have accessed or wanted to access hearing services.
- Live in the United Kingdom.
- Have access to a device that has internet access and is compatible with Zoom (a computer, mobile phone, or tablet).

This study will require you to take part in a focus group, with between 4-6 autistic people. It will take place online, using Zoom. You will be asked about your experiences of accessing hearing services, and your views on how these services can be improved.

Participants will be reimbursed for their time in this study.

For more information or if you are interested in taking part, please visit:

<https://sites.manchester.ac.uk/aldap/>

Or email: [Shanice.Thomas@manchester.ac.uk](mailto:Shanice.Thomas@manchester.ac.uk) or  
[Siobhan.Brennan@manchester.ac.uk](mailto:Siobhan.Brennan@manchester.ac.uk)

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